Abstract

Psychosocial interventions for people with an intellectual disability and dementia: A systematic review

Background: People with intellectual disability experience a higher prevalence of dementia, at an earlier age, than the general population. The aim of this review was to establish the psychological interventions and outcomes for individuals with intellectual disability and dementia.

Methods: A search of eight electronic databases and reference lists of all included articles was conducted using PRISMA guidelines. Data were synthesised using an integrative method.

Results: Initial searching produced 2331 papers. Twenty-one studies met the inclusion criteria. Interventions were deductively categorised into behavioural, systemic and therapeutic. All studies reported positive findings for individuals and for the systems which support them, but limited by methodological issues and neglect of the direct experience and impact on individuals themselves.

Conclusions: The findings are discussed in relation to the wider literature and evidence-base. Future research should aim to adopt methodologically robust designs that are inclusive of the individual experience of people with intellectual disability.

Keywords

Intellectual disability, dementia, psychosocial interventions, systematic review

1. INTRODUCTION

Dementia is a well-established comorbidity for people with an intellectual disability (Cooper, 1997). This is due to increased life expectancy resulting in associated age-related illnesses, and intellectual disability itself being an established risk factor (The British Psychological Society, 2015).

People with an intellectual disability and dementia may have a similar presentation to the general population, including characteristics of a reduction in memory capabilities; changes in mood, personality, and behaviour; impaired reasoning; impaired ability to retain new information; susceptibility to stress; environmental sensitivity; and increasing sensory difficulties (Janicki & Dalton, 2000). However, unlike the changes in memory function that are typically first reported in the general population, the initial presenting difficulties for people with an intellectual disability may be a change in behaviour or personality. This may be due to the function of the frontal lobes being compromised early in the course of dementia (Ball et al., 2006). For those with an intellectual disability, prevalence rates of dementia are higher and dementia occurs at an earlier age, than those in the general population. This is particularly so for people with Down's syndrome, where the neuropathological changes associated with dementia are invariably present before 40 years of age (Evans et al., 2013). Although not all those with these neuropathological changes develop dementia, those who do develop the condition experience a more rapid progression and a significantly increased mortality rate (Coppus et al., 2006).

It is recommended that person-centred approaches are provided by multi-professionals and agencies and that these are tailored to the existing health, disability, and social circumstances of the individual (The British Psychological Society, 2015). These approaches include, where appropriate, the provision of psychosocial interventions which aim to improve cognition; enhance emotional and psychological well-being; reduce behavioural symptoms; and promote everyday functioning and overall quality of life (Patel, Perera, Pendleton, Richman, & Majumdar, 2014). However, psychosocial interventions are not provided in isolation and are typically delivered in conjunction with other interventions that aim to meet the changing needs of the person.

The delivery of psychosocial interventions should be contingent upon a formulation of the multiple influences upon an individual: behavioural, systemic, biological. This then facilitates more effective understanding and treatment. Psychosocial interventions can be orientated towards behaviour, emotions, cognition and stimulation (Kalsy-Lillico, Adams, & Oliver, 2012; Watchman, 2014b).

Despite the presence of disability-focused, person-centred, approaches to care and organisational frameworks for psychosocial interventions (Kalsy-Lillico et al., 2012), there has been a lack of research to establish an evidence base for these approaches for those with an intellectual disability and dementia (Watchman, 2014a). Rather than focusing on interventions, previous systematic reviews conducted in the area of intellectual disability and dementia have focused primarily on clinical presentation (e.g. Lautarescu, Holland, & Zaman, 2017); the assessment tools used for diagnosis (e.g. Elliott-King et al., 2016; Zeilinger, Stiehl, & Weber, 2013); or scoping the needs of the population (Llewellyn, 2011).

Systematic reviews regarding interventions have focused solely on medication (e.g. role of Donepezil; Mohan, Carpenter, & Bennett, 2008).

Consequently, there is a lack of knowledge regarding the psychosocial interventions that should underpin the person-centred care of people with an intellectual disability and dementia (Brooker, 2006). Establishing the evidence base could promote the adoption of evidence-informed interventions, and lead to improvements in quality of life and well-being (The British Psychological Society, 2015).

This systematic review aimed to synthesise the peer-reviewed literature regarding the nature and effectiveness of psychosocial interventions for people with an intellectual disability and dementia. This review aimed to answer the following questions:

- What are the psychosocial interventions for individuals with an intellectual disability and dementia?
- What are the outcomes of these interventions for individuals with an intellectual disability and dementia?

2. METHODS

This review was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Electronic literature searches were performed by the first author in October 2018 using the following databases: PsychINFO, AMED, PsycARTICLES, CINAHL, MEDLINE, ScienceDirect, ASSIA, Google Scholar. Reference lists of articles were also screened by the first author. Search terms were developed assimilating keywords on the topics of dementia, intellectual disability, and intervention(s). These keywords were refined through scoping searches within selected databases. As this review was focused on identifying the psychosocial interventions and gaining an understanding of their outcomes for individuals with an intellectual disability and dementia, the search terms were required to be broad in scope, so as to retrieve all relevant studies. The search terms applied were: dementia; Alzheimer*; cognitive impairment; and memory loss. These were used in addition (using an 'AND' Boolean operator) to the following terms which can be used internationally to describe intellectual disability: intellectual disabilit*; learning disabilit*; and learning difficult*. The inclusion of the latter two terms is important as in some countries, such as the United Kingdom, these are used as alternatives to the term 'intellectual disability'. Finally, these terms were used in addition (using an 'AND' Boolean operator) to the following intervention terms: intervention; treatment; and therapy. The screening and selection processes are summarised in Figure 1.

Figure 1 near here

Table 1 near here

2.1 Data extraction and analysis

A data extraction form was developed using the review questions as an organising framework. Information on intervention, evaluation methods, and the outcomes of the intervention were the focus of the data extraction. In addition, key descriptive information was also extracted.

The Critical Appraisal Skills Programme (CASP) checklists for qualitative studies (Critical Appraisal Skills Programme, 2018b) and case-control studies (Critical Appraisal Skills Programme, 2018a) were employed to appraise the quality of included articles. In addition, the Joanna Briggs Institute critical appraisal checklists for quasi-experimental studies (Joanna Briggs Institute, 2017b) and case reports (Joanna Briggs Institute, 2017a) were also employed. Quality appraisal tools provide quality criteria according to the specific study design. Therefore, four different quality checklists were required to comprehensively assess the quality of all the included studies in this review.

Each quality item was graded as “yes”, “no”, “partially met”, “unknown” (i.e. sufficient information not provided by the study), or “not required”. Overall article quality was appraised as “high”, “moderate”, or “low”, as based on the overall pattern of ratings within each checklist. As there is no guidance available from the adopted quality checklists as to the minimum criteria a study must meet to be defined as “high”, “moderate”, or “low” quality, this was at the discretion of the authors. However, no studies were excluded from this review based on the overall quality rating. This position was adopted to ensure a comprehensive review.

To ensure quality, triangulation processes for eligibility and quality appraisal were enacted. Regarding eligibility, the first and second authors independently assessed the eligibility of all full-text articles for review against the inclusion and exclusion criteria detailed in Table 1. The first author assessed the quality of all eligible studies and the second author assessed the quality of three randomly assigned studies.

To answer the review questions, quantitative and qualitative data were synthesised utilising an integrative method of analysis (Whittemore & Knafl, 2005). Both qualitative outcome data (i.e. themes and supporting quotations) and quantitative data (i.e. descriptive, numerical values, statistical findings) were deductively categorised in relation to behavioural interventions, systemic interventions, or therapeutic interventions. The outcomes of interventions were coded as either positive, neutral, or negative. In addition, positive quantitative data were coded regarding whether or not statistical significance was achieved.

3. RESULTS

A total of 2331 titles/abstracts were considered against the criteria outlined in Table 1. Following this, 169 articles were selected for full-text review. Twenty-one articles met the full criteria and were included in the synthesis. There was a high level of agreement between the two independent assessors, with approximately 85% agreement of studies meeting the inclusion criteria. Typically, a lack of agreement was primarily due to the interpretation of the information presented by studies regarding a diagnosis of dementia, which was not always clearly defined by authors. Therefore, a triangulation meeting was held to discuss studies that did not reach agreement to ensure eligibility criteria were applied consistently and that studies were excluded for the same reason.

Table 2 provides descriptive information for the 21 articles included. There were 106 individuals with an intellectual disability and dementia; 134 support workers/care staff; 15 family caregivers and 29 professionals in these studies. Studies were typically conducted within community and residential services for individuals with an intellectual disability within the UK, with an absence of studies from other countries. The design of eligible studies was either qualitative (*n* = 10), or they were case studies/series (*n* = 8). There were a small number of quasi-experimental studies (*n* = 3).

Table 2 near here

3.1 Quality appraisal

Table 3 provides a summary of quality appraisal ratings. There was a high level of agreement between raters, with approximately 95% agreement regarding quality grades. A triangulation meeting was held to discuss the specific quality criteria of studies that did not reach a blind agreement. A lack of standardised guidance regarding the minimum criteria to meet each quality item, or for the overall quality rating, was influential in the blind disagreement. However, a consensus was achieved regarding the quality of all triangulated studies. Overall, none of the studies were rated as low quality. Two studies were rated as high quality and all remaining studies were rated as moderate quality. In achieving a rating of high quality, these two case reports provided comprehensive histories of the individuals included, whilst acknowledging the complexities inherent in treatment and providing future learning points.

Table 3 near here

With regards studies rated as being of moderate quality, the quality ratings of qualitative studies were typified by a lack of critical examination of the role of the researcher(s) upon the design and/or results; insufficient information presented by the authors regarding recruitment, ethical, or data analysis procedures; and the findings not being clearly or sufficiently detailed. Similar limitations in study quality were present for quasi-experimental studies with a lack of consideration of the role of confounding variables upon the study outcomes; insufficient information presented by authors regarding data analysis, including the influence of inter-rater reliability of adopted measures; and insufficient period of follow-up to assess the longer-term outcomes of the intervention.

Inherent to all case studies/series is a lack of generalisability of the findings as a result of small sample sizes. However, in addition to this, the quality of the case studies/series included in this review was impacted by a lack of a detailed personal, medical, and psychosocial history in providing a contextual frame for the study outcomes; the clinical presentation immediately prior and post-intervention being either omitted or not sufficiently detailed; and a lack of consideration of contextual and/or systemic factors that may have influenced outcomes.

3.2 What are the psychosocial interventions for individuals with an intellectual disability and dementia?

Studies were deductively categorised into: behavioural interventions; systemic interventions; or therapeutic interventions. See Table 4.

Table 4 near here

3.2.1 Behavioural interventions.

3.2.1.1. Behavioural modification. Behavioural interventions were typically focused on behavioural modification, usually delivered through the individual's staff team, with the primary aim of extinction of the behaviours perceived as challenging. Such behaviours were described as running-away, being non-compliant, public stripping, loitering and stealing. Behaviour modification interventions involved reinforcement schedules in order to reduce or extinguish the behaviour, including interval reinforcement (Bowman, 1996); contingent reinforcement (Horovitz, Kozlowski, & Matson, 2010); and differential reinforcement of other behaviours (Vogl & Rapp, 2011).

3.2.1.2. Behavioural Activation (BA). This was used in the study by Green (2017). This approach aims to replace negatively reinforced patterns of withdrawal and avoidance with positively reinforced alternatives (Martell, Addis, & Jacobson, 2001). BA is typically an evidence-based intervention for adults with depression (Sturmey, 2009). It was also recently described as a feasible intervention for individuals with an intellectual disability (Jahoda et al., 2015) with the results of a recent randomised controlled trial evidencing the efficacy of the approach in ameliorating symptoms of depression (Jahoda et al., 2017). Green (2017) made BA accessible for an individual with an intellectual disability, dementia, and symptoms of depression. This case study detailed how the intervention contained the crucial facets of the approach, including the identification of rewarding activities; engagement in activities that promoted pleasure and mastery; alongside activity scheduling and a mood diary. In addition, TRAP (Trigger, Response, Avoidance Pattern) and TRAC (Trigger, Response, Alternative Coping) models (Martell et al., 2001) were used to explore any barriers to engagement.

3.2.2 Systemic interventions.

Systemic interventions are characterised as those that aim to achieve the appropriate care and/or the facilitation of change through indirect working with the individuals, staff, service providers and systems around the individual with an intellectual disability and dementia.

3.2.2.1. Psychoeducational groups. In the study by Lynggaard and Alexander (2004) a dementia psychoeducation group was implemented for individuals with an intellectual disability who were housemates of individuals with a diagnosis of dementia. The group aimed to provide support and information, alongside increasing the group members' understanding of dementia, with the aim of reducing and managing stress through education and problem-solving. A structured group format was adopted, with sessions adapted to the needs and feedback of the group. Sessions included psychoeducation about memory and its processes; living with an individual with dementia; and problem-solving.

Fahey-McCarthy et al. (2009) described how a psychoeducational group was developed specifically for palliative care and intellectual disability staff, due to the need for both groups to increase their knowledge and skills in providing palliative care for individuals with an intellectual disability and dementia. This bespoke group was developed and implemented by a multi-disciplinary team of trainers (including nursing and palliative care physicians) and encompassed 20 sessions covering a range of topics. These included the history and philosophy of intellectual disability and palliative care; ethics, decision making, and the influence of culture; loss, grief, and bereavement; breaking bad news; and end of life care.

3.2.2.2. Environmental interventions. Hemmings and Greig (2007) reported on the evaluation of a specialist inpatient service within a psychiatric hospital that adopted care planning process to meet the multiple health and social care needs of individuals with an intellectual disability, dementia, and associated behavioural difficulties.

Environments were also used as a proactive method. A special care unit was designed to proactively meet the needs of this population (De Vreese et al., 2012). This included training staff members in Gentle Care (Jones, 1996) and the person-centred care model (Kitwood, 1993), who then supported individuals' recreational activities through the adoption of the stimulation-retreat method (Lawton et al., 1998) and the lifestyle approach (Symard, 1999). Individuals also had access to additional therapies, including music and animal-assisted therapy. The unit's environmental design was also adjusted through the use of appropriate signage, daylight, and specific floor coverings (Hoskins & Marshall, 2002).

3.2.2.3. Dementia Care Mapping (DCM). DCM is a tool that has been used to observe and measure the quality of life for individuals with dementia in the general population, with a view to enhancing person-centred care within dementia care settings

(Brooker & Surr, 2005). DCM is typically a three-stage process incorporating: interval time sampling of the interactions and activities of the individual within their care setting, which are subsequently coded with an associated well-being/ill-being value; recording of high quality care and/or positive events; and the processing of all data, which is fed back to both the individual and staff with a view to highlight quality care alongside areas for development. DCM is a well-established model within general older adult dementia care (Capstick, 2003; Surr, Griffiths, & Kelley, 2018), with evidence of good reliability (Woods & Lintern, 2003). This review located four studies that evaluated the effectiveness of this approach within the intellectual disability population (Finnamore & Lord, 2007; Jaycock et al., 2006; Schaap, Dijkstra, et al., 2018; Schaap, Fokkens, et al., 2018).

3.2.2.4. Mediational Intervention for Sensitizing Caregivers (MISC). This was developed with the aim of improving the ability of staff and caregivers to relate to individuals with an intellectual disability, in order to enhance cognitive, emotional, and behavioural functioning through the adoption of operative strategies (Klein, 1988). It is achieved through the integration of three theoretical frameworks: person-centred cultural approaches (e.g. focus upon individual identity and personhood; Kitwood, 1997); rehabilitation approaches (e.g. strategies to compensate for cognitive decline; Clare, Wilson, Carter, & Hodges, 2003); and mediational approaches (e.g. importance of reciprocal relationships; Klein, 1992). Lifshitz and Klein, (2011) utilised MISC for individuals with an intellectual disability and dementia with previous studies evidencing the efficacy of this approach within younger individuals with an intellectual disability (Klein, 1992) and Down’s syndrome (Sobleman-Rosenthal & Klein, 2003).

3.2.2.5. Routine care and support for intellectual disability staff. As outlined, systemic interventions can incorporate specific additional input or methods to support individuals with an intellectual disability and dementia. However, it is acknowledged that the routine care and support provided by intellectual disability staff and service providers is a substantive and important intervention for the care and support of this population. Therefore, the typical care and support afforded to individuals with an intellectual disability and dementia are included within this review (Iacono et al., 2014; McLaughlin & Jones, 2010; Perera & Standen, 2014).

3.2.3 Therapeutic interventions.

These include direct interventions provided to the individual, and/or group of individuals, that aim to enhance their psychosocial wellbeing.

3.2.3.1. Music-orientated groups. These interventions are recommended for the general intellectual disability population (The British Psychological Society, 2009) due to the level of practice-based evidence regarding the efficacy of this approach (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). These approaches have also been developed for individuals with an intellectual disability and dementia. Specifically, a pilot of an 18-session music therapy group (Bevins et al., 2015), which was facilitated by a music therapist and a clinical psychologist. This pilot group adopted a structured group format, including: a welcome song; group and individual playing, including following and mirroring others; taking the lead in the group playing; and a goodbye song. Individuals were encouraged to openly share feelings and experiment playing new instruments. In addition, a “Singing for the Brain” pilot group was developed for individuals with an intellectual disability and dementia (Ward & Parkes, 2017). The “Singing for the Brain” group was developed by the Alzheimer’s Society as a means of using singing as a stimulating activity within a supportive environment to promote social interaction, confidence, and communication within the general older adult population (Alzheimer’s Society, 2012; Montgomery-Smith, 2006). It is typically facilitated by a trained leader, to a defined model, that is inclusive of vocal warm-ups, song requests, and the singing of a variety of songs (Alzheimer’s Society, 2012). The pilot group was facilitated fortnightly by a trained facilitator and day centre staff and was conducted within day services.

3.2.3.2. Memory cafés. The Memory Café is a regular feature of dementia care services within the general population. The aim is to bring together individuals within an informal environment that acts as a safe space to socialise, share information, and provide peer support (Capus, 2005). Typically, activities encapsulate a combination of reminiscence style activities and practical assistance. Kiddle et al. (2015) described a 12-week pilot group for individuals with an intellectual disability and dementia, facilitated predominately by psychology and nursing colleagues. The group included physical, cognitive, and creative activities alongside psychoeducational talks aimed at support workers and carers, which included psychoeducation on dementia; the role of medication; communication; and meaningful activity.

3.2.3.3. Dementia support groups. A further group intervention aimed at supporting and enhancing the quality of life and well-being of individuals with an intellectual disability and dementia was a dementia support group (Rosewarne, 2001). This was primarily focused on the needs of the individuals and aimed to maintain their functioning through engagement in a range of activities, including reminiscence; life story work; cognitive approaches (e.g.

quizzes); and informal reality orientation. The group was facilitated weekly within both day and residential settings by two facilitators with small group numbers (*n* < 6).

3.2.3.4. Life story books/rummage boxes. Life story work has been evidenced to aid communication (Hewitt, 1998) and remembering the past (Porter, 1998). Further life story work, in the form of life story books (i.e. written memories, pictures of important people, places, events) and rummage boxes (i.e. meaningful multi-sensory items associated with past experiences, people, and/or places) has been explored with people with an intellectual disability and dementia (Crook et al., 2016).

3.3 What are the outcomes of the psychosocial interventions for individuals with an intellectual disability and dementia?

The data from all studies within this review were reviewed and categorised into positive, neutral, and negative findings to provide a comprehensive understanding of the outcomes.

3.3.1 Outcomes of behavioural interventions.

Amongst these studies, outcomes were measured through the incidence rate of the targeted behaviour, pre and post the implementation of a reinforcement schedule. The period of the intervention phase (i.e. implementation of reinforcement schedule with therapist supervision) ranged from 8 weeks to 16 weeks. There was extinction of the targeted behaviour at the conclusion of the intervention phase, utilising interval reinforcement (i.e. of running-away behaviour at 8 weeks; Bowman, 1996) and differential reinforcement of other behaviours (i.e. of loitering and stealing behaviour at 12 weeks; Vogl & Rapp, 2011). In addition, there was a

61.11% reduction in the targeted behaviour (i.e. non-compliance) following a 16-week intervention programme using contingent reinforcement (Horovitz et al., 2010).

Despite significant reductions of the targeted behaviour immediately following the intervention phase, the results at follow-up varied in these studies. Specifically, non-compliance behaviour continued to decrease (i.e. to 85.22% reduction) at one-month follow-up (Horovitz et al., 2010) with staff continuing to employ the contingent reinforcement schedule unsupervised. However, when reinforcement schedules were discontinued by staff outcomes varied, with evidence of sustained behaviour extinction at three months (Vogl & Rapp, 2011) and the reoccurrence of the extinct behaviour at six months (Bowman, 1996).

The outcomes of the BA intervention were primarily focused upon the individual's symptoms of anxiety and depression. These were measured using the Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID; Mindham & Espie, 2003), and the Glasgow Depression Scale for People with an intellectual disability (GDS-LD; Cuthill, Espie, & Cooper, 2003). Outcomes suggested a clinically significant improvement in symptoms of anxiety and depression following BA, alongside increases in activity engagement and problem-solving. However, the latter was not formally assessed.

Despite positive outcomes of behavioural interventions, there are a number of limitations. Specifically, the outcomes of all behavioural interventions included in this review were measured within a case study design, which significantly impacts the generalisability of the results. Generalisability is also impacted by the unstandardised, individually-tailored behavioural interventions; which were either constructed following a psychological formulation of the individual's targeted behaviour, or required adaptation in line with an individual's specific cognitive and functional abilities. Therefore, the ability to generalise these interventions to other individuals with an intellectual disability and dementia is severely limited. In addition, the outcomes of behaviour modification interventions were solely focused on the incidence rate of the targeted behaviour and failed to incorporate additional outcomes (e.g. quality of life, caregiver burden) that would have provided a more comprehensive understanding of the impact of these interventions for this population.

3.3.2 Outcomes of systemic interventions.

The psychoeducational groups identified within this review typically reported positive outcomes. The dementia psychoeducational group delivered to the housemates of individuals with an intellectual disability and dementia (Lynggaard & Alexander, 2004) reported an increased understanding of dementia and its associated symptoms. This, in turn, promoted feelings of understanding and empathy for individuals with dementia and resulted in improved support, interactions, and quality of life. In addition, the psychoeducational group that provided support for the delivery of quality palliative care (Fahey-McCarthy et al., 2009) was highly valued by staff; addressed key training needs of the staff groups; enabled staff to prepare individuals for a good death; and supported them and others regarding the process of grief and bereavement. However, akin to the behavioural interventions, these psychoeducational groups were devised primarily to meet the specific unmet needs of the participants. Therefore, the generalisability of these interventions is inherently limited. However, there is substantive clinical value in delivering interventions that are tailored to the needs of a specific population.

Particular environments as interventions for individuals with an intellectual disability and dementia also produced positive outcomes. A specialist dementia-informed environment (De Vreese et al., 2012) noted improvement in cognition and the stabilisation of everyday functioning as measured by the Dementia Questionnaire for Persons with Mental Retardation (DMR; Evenhuis, Kengen, & Eurlings, 2009) in comparison to controls who accessed a day-care service or were resident in a nursing home. However, these improvements did not reach statistical significance. In addition, a specialist inpatient service (Hemmings & Greig, 2007) produced improvements in physical health, well-being, and quality of life for an individual with an intellectual disability, dementia, and a comorbid mental health condition. The authors suggested these outcomes were contingent on access to the expertise of multi-disciplinary health care expertise, which was coordinated by an enhanced CPA. However, both studies did not sufficiently account for, or control, the influence and impact of confounding variables upon outcomes. As individuals are exposed to many variables that may impact outcomes (e.g. additional therapies) it is difficult to make conclusions as to the active ingredient(s) that facilitated the reported change. In addition, researchers either did not use any objective measures of the outcomes reported (Hemmings & Greig, 2007) or used indirect general measures of global functioning (De Vreese et al., 2012), which limited the methodological rigour.

The use of DCM remains in its infancy, both clinically and empirically, for individuals with an intellectual disability and dementia. However, all studies included in this review reported positive outcomes following the adoption of this approach. Specifically, that it is appropriate and feasible for the population (Schaap, Dijksra, et al., 2018; Schaap, Fokkens, et al., 2018); it provides new knowledge and skills for staff who subsequently felt empowered (Finnamore & Lord, 2007; Schaap, Dijkstra, et al., 2018); and it supports care planning, with positive changes in care plans noted (Finnamore & Lord, 2007; Jaycock et al., 2006). However, there were a number of organisational barriers (e.g. staff resources) in the implementation of the approach (Jaycock et al., 2006). Despite DCM evidencing positive outcomes for staff and services, there is no evidence regarding the impact upon the individual’s quality of life, which is central to the aims of the approach.

The outcomes of MISC were obtained through a case study design (Lifshitz & Klein, 2011) with the primary outcome measure (DMR; Evenhuis et al., 2009) evaluating social, adaptive, and cognitive functioning. MISC did not produce significant change on the individual’s DMR score on any domain. However, clinical opinion suggests increased capacity and motivation for learning new skills to compensate for the associated cognitive deterioration. However, as this study utilised a case-study design with a lack of direct measures, it is with caution that these findings are interpreted.

Studies investigating routine staff support as an intervention for individuals with an intellectual disability and dementia utilised qualitative methods to examine outcomes. The outcomes of these studies suggest that staff can have a limited understanding of dementia, which leads to the adoption of strategies based on trial and error, which subsequently results in a lack of consistency across the team (Iacono et al., 2014). Therefore, staff require timely and effective support from specialist health services (McLaughlin & Jones, 2010). Staff also utilised a number of strategies to minimise personal stress to aid effective care for the individual, including: (a) holding a narrative of the individual as a person; (b) practical problem-solving; and (c) compartmentalisation of difficulties (Perera & Standen, 2014). However, as studies typically employed small sample sizes, these findings do not represent the experience, knowledge, and skills of all intellectual disability care staff.

3.3.3 Outcomes of therapeutic interventions.

Music-orientated therapy groups evaluated outcomes qualitatively, adopting thematic analysis (Braun & Clarke, 2006). Across both the music therapy group (Bevins et al., 2015) and the “Singing for the Brain” group (Ward & Parkes, 2017), individuals were reported to find the group to be pleasurable and enjoyable. In addition, benefits in social interaction and communication were identified. In addition, staff queried whether the “Singing for the Brain” group may have a longer-term benefit on mood (Ward & Parkes, 2017), however this was not formally assessed. A similar improvement in affect was evidenced for individuals attending a pilot Memory Café (Kiddle et al., 2015), alongside increased communication, interaction, alertness, and participation.

Outcomes of the dementia support group (Rosewarne, 2001) were evidenced through a case study of a group participant. The individual exhibited improvements in orientation, the ability to learn new information and concepts, and quality of life. However, in accordance with the dementia diagnosis, there was a deterioration noted in short-term memory. Improved well-being was also evidenced for both of the therapeutic interventions derived from life story work (i.e. life story books and rummage boxes; Crook et al., 2016). However, there were individual differences as to which of these interventions promoted well-being for each individual, reflecting the influence of personally meaningful interventions on outcomes. It should be noted that outcomes of these interventions were significantly impacted by a lack of methodological rigour, including studies failing to adopt analytic methods (Kiddle et al.,

2015) or measures (Rosewarne, 2001), relying instead on clinical opinion and descriptive outcomes.

4. DISCUSSION

This review aimed to synthesise the literature regarding the nature and outcomes of psychosocial interventions for the care of individuals with an intellectual disability and dementia. There has been a lack of an established evidence base for these approaches, with previous reviews regarding interventions focusing on medication (e.g. Mohan, Carpenter, & Bennett, 2009).

Psychosocial interventions were deductively categorised into three distinct categories: behavioural interventions; systemic interventions; and therapeutic interventions. This categorical framework is in keeping with the organisational framework of psychosocial interventions outlined by Kalsy-Lillico et al. (2012), where interventions were orientated towards behaviour, emotion, cognition, or stimulation. The main difference is the integration of emotion, cognition, and stimulation interventions into the broad category of therapeutic interventions. This was due to the relative absence in the literature of psychosocial interventions that were conducted directly with an individual. Instead, the focus primarily was centred on systemic interventions, which aim to improve the psychological well-being and quality of life of individuals indirectly via systems and models of care.

Despite the relative scarcity of direct therapeutic interventions for individuals with an intellectual disability and dementia, the interventions within this review are comparable to the nature of direct therapeutic interventions established within the general older adult population

(Johnston & Narayanasamy, 2016). However, there are some differences. For the general older adult population, there is a wider application of these interventions, such as the use of technology in life story work and greater methodological rigour in the studies evaluating the approaches. Thus, despite the positive outcomes evidenced in this review, including a reduction in the rate of behaviours that challenge; an improvement in the systemic care and support; and enhanced psychological well-being and quality of life for individuals; outcomes are tempered by methodological limitations. These limitations include limited external validity due to study design or individually-tailored intervention; a lack of analytic methods; no control of confounding variables; and a lack of examination of wider, yet important, outcomes, such as quality of life or caregiver burden.

An important limitation of the studies included in this review is the lack of direct inclusion of the individual with an intellectual disability and dementia when examining outcomes. Specifically, studies opted for exploring outcomes for the individual from the perspective of staff (e.g. Bevins et al., 2015; Ward & Parkes, 2017) or used observational, rather than direct, measures when assessing outcomes (e.g. Crook et al., 2016). Despite over 30 years since the normalisation movement (Wolfensberger, 1982) was criticised for the exclusion of the voice of the individual with an intellectual disability, it appears that the lack of representation and the imbalance of power continues to permeate within research. This may be, in part, due to ethical issues regarding capacity to consent (Calveley, 2012). However, safeguards derived from the introduction in England and Wales of the Mental Capacity Act (2005), including the role of personal and nominated consultees, should serve to alleviate such issues. Researchers need to also weigh up the ethical implications of excluding this population from research altogether. Patient and public involvement is increasingly seen as a key component of health and social science research. However, a recent systematic review of co-research with people with an intellectual disability showed that less than half of the protocols reviewed reported such involvement (Di Lorito et al., 2018). Involvement of people with dementia in research can create benefits such as empowerment of the individuals themselves and challenging of academics' traditional views of research processes and data-gathering ((Di Lorito et al., 2016).

The lack of a synthesis of psychosocial interventions within clinical practice, and the associated evidence, has invariably led to a lack of knowledge in practice. This is clearly evidenced by the omission of psychosocial interventions within established intellectual disability and dementia care pathways (e.g. NHS East and North Hertfordshire Clinical Commissioning Group, 2018; Harlow, 2008). Therefore, it is hoped that this review will inform staff, professionals, and services of the available evidence and promote the utility of these interventions, where appropriate, within clinical care pathways. Within a local NHS Trust, the outcomes of this review have been shared within integrated health and social care intellectual disability services, which has directly resulted in a review of the current care pathway with a renewed focus on quality of life and psychological well-being post-diagnosis. In addition, with the absence of literature in this area, it is hoped that clinicians will continue to disseminate the outcomes of routine clinical practice with this population.

With regards to future endeavours, it is imperative that substantive empirical research is conducted to enable parity with the general older adult population. Research should aim to explore, through qualitative and quantitative methodologies, the experience and impact of psychosocial interventions for individuals with an intellectual disability and dementia. Outcomes should be assessed across a number of areas including behavioural, cognitive, and emotional domains. In addition, outcomes should be measured using, where possible, direct objective measures (e.g. Severe Impairment Battery, for the measurement of cognition, Saxton, Mcgonigle, Swihart, & Boller, 1993; Maslow Assessment of Needs Scale – Intellectual disability, for the measurement of quality of life, Skirrow & Perry, 2009) and/or qualitative methods directly employed with individuals with an intellectual disability and dementia. This would not only improve the methodological rigour of research in this area but would go some way in readdressing the power imbalance and lack of representation, which has been crucially absent.

A promising psychosocial intervention recommended for the management of dementia in the general older adult population is Cognitive Stimulation Therapy (CST; NICE, 2006). This is typically a seven-week manualised programme delivered by a healthcare professional to the general older adult population with a diagnosis of dementia (Spector, Thorgrimsen, Woods, & Orrell, 2006). Structured group activities, which aim to be stimulating and engaging, are offered with flexibility within a safe, supportive and respectful environment that is free from pressure and judgement and promotes positive peer relationships. There has been no empirical research examining the effects of this intervention within the intellectual disability population. This is despite an explicit recommendation to examine its feasibility and outcomes (The British Psychological Society, 2015). Research into the effects of this intervention for people with an intellectual disability and dementia is needed.

In providing a systematic review of the literature regarding disability-focused, person-centred, psychosocial interventions for people with an intellectual disability and dementia; this review will provide essential knowledge in enacting a key recommendation in England. Specifically, that all individuals diagnosed with dementia and their carers will have access to meaningful post-diagnostic care, including social and psychological care and support (Department of Health, 2015). Furthermore, this review will supplement the recently published National Institute for Health and Care Excellence (NICE) guidance on the care and treatment of individuals with an intellectual disability as they grow older (NICE, 2018), which has focused on social and vocational interventions for all older adults, irrespective of dementia diagnosis. Lastly, this review will provide crucial evidence for organisations such as the Dementia Action Alliance, created as a result of the "Living Well With Dementia: A National Dementia Strategy" (Department of Health, 2011), who bring key organisations together to promote and share best practice for individuals with dementia in marginalised groups, including individuals with an intellectual disability (Dementia Action Alliance, 2017).

This review has attempted to ensure quality and validity through the adoption of triangulation processes, although it is acknowledged that the reference list screening by one author may have introduced biases. In addition, no techniques were employed to ensure bias was adequately accounted for in eligible studies. Furthermore, this review is limited by its lack of systematic searching of the grey literature. This is of particular importance in an area that may yield practice-based research and dissemination of routine care which may be accessible only within grey literature.

5. CONCLUSION

This review synthesises the literature regarding psychosocial interventions for individuals with an intellectual disability. Current and/or historical interventions can be categorised into behavioural interventions, systemic interventions and therapeutic interventions. All interventions reported positive findings for both the individual (e.g. in affect, quality of life) and for the systems which support them (e.g. improved understanding and knowledge). However, research in this area is limited by the lack of methodological rigour and fails to be inclusive of the direct experience and impact of these interventions on the individuals themselves. In addressing this imbalance, future research should aim to adopt methodologically robust designs that are inclusive of the individual experience.

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